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Jean Tydings interview for the Lest We Forget Collection of Oral Histories

Jean Tydings

Jeff Moyer

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JEAN TYDINGS

Jean: The concerns that people have. Some of the people have been writing letters. I was on a citizen's advisory board with and I always am amazed at what I think more than anything people feel guilty for placing their sons or daughters in state institutions when they had no choice. They were just told that by doctors when their children were young, this is what you need to do. People always listen to the doctors. There were no options. So people placed their son or daughter in an institution and as time has evolved things change. Sometimes it's hard to make that change. It's like moving from one house to another. You buy a house in a certain area and you expect that the value is going to go up but sometimes it doesn't happen and it's just time to move on. It's the same thing in life when you expect that this job is going to be a good job and turns out not to be the job you wanted and people's living situation especially when we're making the choices, sometimes you have to move on and give them what's better now because it wasn't there then. I feel bad for parents that feel that maybe they made the wrong choice. They didn't. They made the only choice they had. But now it's time to give people better choices and options. The fear is just so great and overwhelming.

Jeff: The date is July 15, 2003; this is an interview with Jean Tydings. We're interviewing in Akron, Ohio the Lest We Forget project. Jean, you have very extensive background in dealing with both state institutions and community reintegration. What is your first experience with state institutions?

Jean: My first experience I had started with the ARC of Summit Portage County 26 years ago and I went down with my boss at the time who is Ray Thomas. We went to Columbus State Institution for a meeting. Upon entering that there was a huge concrete sign that said State Institution for Imbeciles, Idiots and Morons. That was an overwhelming statement to me. It was just a statement about people that had been reduced to words because they happened to be born to learn a little bit slower. That was my first experience. We then went in and toured the institution. I've been in several institutions since then and they've been downsized there's no question about that but they still are institutions and large numbers of people are congregated together simply because they learn slower than other people.

Jeff: What did you see when you went into the state institution in Columbus?

Jean: Lots of people on wards half dressed just sitting on benches with nothing to do, just waiting for the time to pass. It was sad. It smelled of an institution and there were just people sitting there, just waiting, nothing, absolutely nothing to do, just watching the time go by or picking on the person next to them because they had nothing else to do—a lot of self-stimulation and waiting.

Jeff: Did you have a tour of the entire facility?

Jean: No, that day we didn't. We went through some of the buildings but then we had a meeting on the state grounds that day.

Jeff: Did you go back to other institutions and see more?

Jean: Yes, I've been to Columbus State Institution a number of times. I was at Apple Creek State Institution a number of times. I was on a citizen's advisory board there. I've been to Gallipolis which was years ago and the institution in southern Ohio, Orient. That was later upgraded to a prison and I use that term very strictly, it was updated so it could become a prison. Six months earlier when I was there just before it had closed there were still rooms with masses of people just sitting and waiting. But six months later when they closed it they had to spend millions of dollars to upgrade it so it was workable for a prison. For individuals that had committed crimes against society but I go back to individuals that happened to be born and learn a little bit slower than the rest of us were placed there for other reasons.

Jeff: Did you see anything that shocked you beyond the masses of people on benches in the buildings?

Jean: When I was Apple Creek and I had been on a number of tours there I would meet people that I always wondered how they ever got there. I always wondered about everybody that was there. But then I would meet people that were very articulate. One guy was there and he was in his late 80s at time and he told us he was there because he had allergies and he had a seizure at one point and so he was placed there. It was mostly due to the allergies. His wife just placed him there. He spent the rest of his life there. The man was extremely articulate but he worked the fields and he talked about when he worked the fields at Apple Creek. He would go out and he would work and he would come at the end of the day and his eyes would be swollen shut from the hay fever but he would make his dollar for the day. Those were the kinds of things that shocked me. To be able to talk to people who could tell me what life was like there. They weren't bitter. That's the other thing that always surprised me. People that have lived in such circumstances but aren't bitter people. They're overwhelmingly accepting of anybody that comes in to talk and spend time with and never forget who you are. Many of the folks that I've met that have lived in state institutions if I've met them once I can see them five years later and they'll call me by name. That always amazes me. It must be because that was so important to people. People coming in and talking with them had to have been so important because they got so little of it when they were in institutions.

Jeff: Were you aware of any abuse or violence or neglect?

Jean: When I was on the citizen's advisory board we were always updated on abuse and neglect that was going on. It was a monthly meeting and we would always be advised of the types of things that were happening. I was always appalled to hear some of things that happened. More appalling to me was the lack of things that could be done. Because of union situations people were protected. Even though we would hear from union members and there are a lot of good people that work with individuals that work in institutional settings but it was easier to be in an institutional setting and have cover up for people abusing other individuals. But stuff would be brought to us about people being beaten with belts and everybody knew what happened but nobody was talking about it. With investigations that would go on that were never finalized because it was too hard. You would have the individuals with mental retardation and the person without and, of course, the people with mental retardation couldn't give you accurate information according to what people thought. So the person that had abused was oftentimes exonerated. That bothered me. It would bother anyone to see that. That cover-up happened a lot. Even though people wanted it to change it's very difficult to change that when you put a person or two people in a room with 25 folks abuse is going to happen. People when they have nothing to do—idle hands create problems and abuse happened a lot. It didn't always get resolved or couldn't be resolved because it wasn't handled properly and the union then said you can't do this and I don't even think the union always agreed with what was going on or how but they were the laws of the union. So people were protected. Even though I remember once sitting there in an advisory board meeting and a union person saying the unions were devised to protect the people that live here and they weren't. They were devised to protect the staff. The people that lived there had to live by the union rules that oftentimes hurt them.

Jeff: What other examples.

Jean: I talked to staff that had talked about seeing abuse that they tried to report. I've talked to individuals. I talked to one individual who told me about how she would see people—she hated going in basements—she lives in the community now but she hated going in the basement. When she would go to the psychiatrist they would put her on medication because they thought it was a

problem that she was having. Finally one day a staff person that was with her in the psychiatrist's office said to her, "Why do you hate going into the basement?" She said because at Apple Creek that's where they would do the shock treatment. So she had a good reason for hating to go into the basement. Nobody ever asked her. So she would see that stuff. I talked to individuals that would see the person next to them being molested and they would just lay in bed at night and pray that no one would come and do that to them.

Jeff: Molested by—

Jean: By staff and it was late at night and once that person ? and people knew what was going on. Certainly the residents knew what was going on but nobody was listening. A good friend of mine who has since passed away talked about the types of things that she lived through at Columbus Developmental Center; when she would run away because she hated it and she would be brought back and the things that would happen to her or the things that would happen to friends of her. She described to me one time which was exactly tarring somebody. They would take this black stuff and put it in their hair and on their bodies. It was just like being tarred and feathered that stuff that I read about in medieval times and she was telling me about this. She said she only ran away once. She never did it again because that happened. She said it smelled awful. The clothes that people wore when you talk with Betty she'll tell you. They had no choice. They had no choice in what they ate. They had no choice in who they talked to, who they slept with. They didn't have a choice in any of that. The other thing that I remember very distinctly in walking into an institutional ward was seeing rows of people who were very physically involved with their disabilities. Just laying there in these beds and flies upon them. Because it was hot, there was no air conditioning so the windows were open and there were just flies swarming around people. I think the other overwhelming story that I heard about an individual at Apple Creek was there was a building called the C building and it was a prison building basically. When people got in trouble they would go there. There was a woman that I worked with; another person was living in the community that ended up there a lot. She would tell stories about how she would eat. They would just open the little window where they could talk to somebody they didn't look at people very often and would throw in a sandwich. There was a hole in the middle of the floor and there was nothing on the floor to sleep on. They slept on the hard cold floor is what she said. But there was a hole in the middle of the floor and they would hose it through the bottom under the door there was a little opening. And they would put a hose through it and that's how they would hose it out at night or when they ever chose to, to clean out the defecation and it would go down the drain then. But that's how people lived because they had behavioral issues frankly that I would have had if somebody had treated me that way.

Jeff: What period was that going on?

Jean: That was probably in the 70s, she lived there. She moved out shortly after I started working here. The C building has since been razed. I'm sure that there are lots of stories that have happened in that building. I just have met a few people that lived there, that spent a lot of time there. I don't think people actually lived there every day. She would get to go back to her living quarters at some point and then would have another problem and go back. But she spent a lot of time there.

Jeff: When you were on the citizen's advisory committee were you involved with only the stories of abuse and neglect that were brought to you or was there a broader development?

Jean: Our responsibilities were to oversee as an advisory committee what was going on. So we got a lot of reports. We met different superintendents because they passed through. I wasn't there during the main time when Apple Creek was really under scrutiny and the lawsuit occurred. We were able though to look at what was going on with folks. There was always concern and one of

the things that happened as a result of the lawsuit, I think it was Delaney vs. the State of Ohio was the original lawsuit, was that people that leave Apple Creek now there's still a consent decree that follows them or should follow them. People that leave Apple Creek have to go to a living situation that is equal to or better than the place that they're leaving. That was a good thing that happened as a result of that. At least we knew it was going to be a better place hopefully and at the time it certainly couldn't be equal to was you could find that anywhere in any other institution but hopefully the better to is the part that they look at. So we were appraised a lot of people moving out. What was going on with those individuals, we talked about the guardianship issues and sometimes those were difficult to have a general guardian over numerous people; nobody really watching out for individuals. Some of the things have changed as a result of that. There are guardian services that have smaller caseloads to make sure the people are being followed. It still is difficult when you've got 20 people on your caseload, how do you effectively act as a guardian for somebody. We as an agency have pushed for individual guardians for every person. Then we've done some of that worked with the Summit County Probate Court to do that. But at Apple Creek those were the things that ? what was going on with individuals when a building was going to be razed, when people were being moved and there was a lot of concern. Most of the people on that advisory board were people that were parents of individuals that were still living there. So I oftentimes buck the system because I had a different viewpoint. And understandably so my child wasn't living there. I was coming from a community minded situation where I believed that there's nothing in the four walls at Apple Creek or any other state institution that can be done in the confines of those four walls that can't be done in the community. I will never understand if it can be done there then if there is something good going on there why can't we bring that to the community where there's less of a chance for abuse because the neighbors are looking out. The people are looking out when somebody goes to the Y or to the workshop or wherever they happen to go during the day. People are looking out for that individual. They're not within the confines of the state institution where the doctors, where the dentists were if they did have those the nurses were people didn't leave unless they were dying to go to a hospital. They would stay on the institution so abuse was easily covered. It can't be done that way in the community.

Jeff: What quality of medical and dental care did you—

Jean: It has improved. It was poor. I personally believe that a lot of people died in state institutions because of the poor medical and dental care. The woman I talked about, Ruby, earlier who had lived at Columbus and she had lived at Apple Creek both she had awful dental care. She didn't have any teeth when she left because her dental care had been so poor. Do I think it was because she didn't brush? I don't think so. I think it was that she didn't have any kind of quality dental care. Medical care, I think many people died at young ages and we're seeing people living longer lives now because the medical care is so much better. It didn't happen in institutions. Again everything happened on the institutional grounds. I've read horror stories but I didn't see the results. I saw the results of poor medical care and dental care for people that had dentures at the age of 35 or didn't have any teeth I should say. When it was time to get dentures they weren't comfortable because it had been so long since their teeth had been pulled. I've seen those kinds of things but I never saw a dentist actually providing treatment or doctors providing treatment. I only know the results of people getting poor care.

Jeff: How many years did you serve on that committee?

Jean: I believe I was on the advisory committee for seven years. I got on the citizen's advisory committee because I had gone to a couple meetings because we were concerned about some of the things that were going on at Apple Creek from an advocacy standpoint. Somebody invited me to go on the committee. It's one of those things. I'm not sure if it was a good thing. It ended up being

a good thing. I learned a lot by being there and met a lot of people and understood a lot of reasons why people did what they did. Parents did what they did at the time. Now we just need to move on so that people are in better places because there are better places out there.

Jeff: After your involvement with Apple Creek describe what your work was and how it was engaged in community reintegration.

Jean: Even while I was on the citizen's advisory board at Apple Creek I was still working for the ARC and the ARC has always been an advocate for people living in the community. When I first started here the group homes, residential setting for people, were 16-18 people in a resident setting. One of the first ones that opened right after I started was for nine people and that was real innovative. We're now to no more than four people living in a setting which is wonderful. It gives people more choices. It gives people the opportunity to maybe have their own space for the first time in their life instead of sharing a room with three other people which is amazing to me that people who are 50-years old or 60-years old have never had their own bedroom, their own personal space. So we've come a long way in providing people more personal things in their lives, just personal space in their lives. Other things that I have seen happen, people are much more independent in where they go and where they work. People that were apprehensive about moving from Apple Creek or other state institutions to where they are now are just worlds apart. They love the independence and when you talk to Betty you'll hear that. The opportunity to travel, the opportunity to pick up the phone and call somebody when she wants to, she does that with me frequently. My family all talks to her. The opportunity to choose what's she is going to have for dinner or to not eat if she doesn't feel like it. To come and go as she pleases, to hop on the bus, to choose what she's going to wear, she gets to make those choices. Where she's going to work and who she's going to talk to, she gets to make those choices. Those things are just far and above better for individuals that live in the community than people that live in institutions didn't have. There's been a whole lot of progress. More than anything it's just I think the movement to the community was providing more human dignity in people's lives. What more can you ask for in life is giving somebody their own dignity and self-worth.

Jeff: Roughly how many people have you been involved with moving back into the community?

Jean: When they were first starting the deinstitutionalization movement in Ohio, strongly starting it, that's when I was at Gallipolis I had gone and reviewed records for individuals because we had to review them for them to come back here and they had set up a way to go about doing that. One of things that I was absolutely astonished at was the lack of records for people. People that have lived in a place for 30 years, there was nothing on them. I was absolutely amazed by that. ?? someplace it's out there. There was nothing on these folks. I wonder where the FBI is. We talk about big brother being in our lives. It's not there for the people that live in institutions. Nobody's watching out for them. I was able to go in and start reviewing some of the files and look at some of those things on individuals to see what type of services that they would need when they came out. If they needed somebody to be with them all the time, if they needed somebody just to be able to hear what they were doing as opposed to watching them 24/7. Or could they travel independently? It was real hard to make those assessments because of the lack of information. I interviewed staff that had worked with folks. Those are always the best resources, people that worked directly with individuals and they always had a lot more to say about people than what was written down anywhere. We saw people progress from little paperwork to coming back to the community and now living full lives. Some of the folks that I did that for probably I recommended full visual supervision and I bet none of them have it at this point because of the lack of records and the limited stuff that we had seen. I just thought of another story of an individual. The very first person I met in Ohio when I moved here had moved into the very first

residential setting I'd gone to and it was for nine folks. The ARC actually started that and spun it off as an independent agency. This guy was on a tremendous amount of medication. When he'd been here for a couple of years and was doing lots of stuff they started seeing some of the effects of medication, tardive dyskinesia some of those types of things so they started to say we need to start removing him from this. So they went back and started to look at the history as to why he was on that medication. There was no information on it at all. Even a greater tragedy than that was that as they started to take him off his body had become so accustomed to the medication that they couldn't take him off of everything. Because he was having more adverse effects by being off of it than being on it. So here was this man who was on medication that nobody could identify as to why and when they tried to take him off of it, they got him off of some of the stuff, but he was never medication free because his body needed it at that time. That is one of the saddest cases I can point to and he died, Tom died a couple of years ago in a nursing home with lots of effects I'm sure were brought upon by the medication.

Jeff: How old was Tom when he died?

Jean: When Tom passed away he was probably 58 or 59 years old. Probably the last five years of his life were very difficult because he was having all sorts of memory issues. He lived in a nursing home and the part of his life where he lived in an institutional setting was tragic. He got to live in a community setting and did a whole bunch of neat stuff and then they resorted back to an institutional setting, a nursing home setting because the care that he needed I believe mostly because of the medication that he had taken all of his of life. He ended up being in a very glum situation at the end of his life also. But he at least had people who cared for him at that time.

Jeff: Describe your involvement with Betty.

Jean: I met Betty when she had moved back to the community. I believe her grandmother had gone and pulled her out of the institution. I met Betty shortly after that. Didn't have a lot of independent skills at the time that was because of the institution; she had potential for everything prior going to the institution. She was institutionalized at a very young age, 16-17 years old, which is not as young for other people but for her was young. She has been an aid, loves kids, it's one of things that she loves most and that's the thing that she desire to do is work with kids. My daughter absolutely adores her. Betty would do anything for my family as we would for her. She worked in the community as an aid in a child-care setting but the hours ran out of that. They loved her they just didn't have the funding as many things have happened in our society. She worked with adults who have other physical disabilities in workshop setting. She's very compassionate, she's real intense. She is one of the kindest gentlest people I've ever met and has had one of the most difficult lives of individuals I've ever met. She's had other medical issues since she left the institution and had to be institutionalized in a nursing home for about six months while she was recuperating. Probably better than most any other person I've ever seen she worked so hard to be able to get out. She now lives independently. People didn't think she would be able to do that. She lives in her own apartment which she loves because she doesn't want a roommate because they'll bug her. She likes her space. One of the things that she does is gather things which is very much institutional behavior and we've been working on that. She'll pick up stuff and keep it. Because that's hard when she's never been able to do that and now she is it's the reverse effect of that. So she has some difficulty with that but she's just the kindest person and she makes my day when she calls. She gives me a hard time and I give her a hard time right back. You'll she that real fast when you meet her. But she speaks her mind, she's involved with people first. She's one of the first people in this area that became involved in the statewide people first program. Absolutely loves that, loves meeting other people and talking to them. She will absolutely tell you what she thinks

about institutions what it meant to her and what it did to her and what it's done to friends of hers. First hand knowledge is overwhelming that she has.

Jeff: What's Betty's current family involvement?

Jean: She has a sister that she sees occasionally. She has more friends than family in the community. She has some very good friends that she has met through church and they've become her family. She's traveled with them. She travels to meet people that have been involved in her life that no longer live in the area. But her one sister is important to her and she sees her on a fairly regular basis, monthly basis and talks with her. Talks with some cousins whenever I go out with Betty she generally sees somebody that she knows. She always sees somebody that she knows but she might see a relative and will introduce me to who that person is. So her involvement in the community is much broader than just family. She's embraced the community as the people that have met her have embraced her into their lives.

Jeff: You talked about Betty's gathering things. What was her experience and what do you know about the experience of people concerning possessions and personal effects in the institutions.

Jean: One of the things that Betty will tell you about is the use of the chicken dresses that they wore. That's what she calls them. That's what they wore; they were not given a choice. It was not a fashion statement she'll tell you. They had to wear these dresses that were just awful. They didn't have a choice. That was what they were given. They didn't have possessions. One of the things that always amazed me about walking into institutions and I don't know because I didn't know Betty when she was at Apple Creek but people that walked around with rings or rings full of keys and they maybe didn't open a door but part of it was because my understanding was because so many staff had rings to open doors. So if people had those things they felt more important. I would see people when I would walk through any state institution and you see folks with rings with 30, 40, 50 keys on them. You never knew if it was a staff person or if it was person with a disability; but a lot of the folks with disabilities that was a possession that they were able to gather. The clothes were limited and if they got new clothes they were oftentimes missing. You would walk into institutional rooms and there weren't pictures on the walls as they got more personal the colors were a little better but the seats were still the plastic seats and the bedspreads were all the same. So even if there were things that tried to make things more personal they weren't really personalized. It was still okay this works best for this room and these four people will live in this room on this pod or this quad or whatever the terms were that they were using at the time to describe where people lived. It was never their bedroom. It was a pod or a quad which kind of tells you how personalized things were for people. How do you personalize four concrete walls that have four or six or eight or 28 beds or whatever in it?

Jeff: Could you describe the chicken dress a little more?

Jean: Betty will have to describe the chicken dress for you and she will. One of the things I've done with Betty, we've talked to legislators. I should say we, I've talked to Betty as she's talked to legislators, because her story is so powerful. I knew these things from Betty just from having spent so much time with her about what was important to her and what wasn't and why. So I would ask her, okay Betty tell me what it was like at Apple Creek and then she would talk about the chicken dress and she would talk about the no phone calls. She would talk about all those things. One of the biggest fears Betty still lives with at this point is going back to the institution. There's nothing I can say to her as much as she trusts me and I think she would trust me to walk across water if she needed me to do that. She would think I could do it. There's nothing I can to her that will convince her that will never happen because it shouldn't have happened to begin with. There's nothing I can say, she knows that as long as it's there. We went back to visit one time and she wanted to do that. She was scared to death that we were going to leave her there.

There were a group of us that went back and she asked to go with us. I killed me to see how frightened she was that she was going to be there. Betty is extremely talkative. We went out to eat afterwards and she didn't shut up after we left because it just all came out. She just felt so much better that we didn't leave her. That was never my intention, would never be my intent for anyone and she knows that. But the reality is she was left there and that's always going to be with her. I would imagine it's going to be with every person that's ever been in an institution. So for us to say that they're okay as long as they're just for people that need it for short temporary period of time there is no such thing as short temporary in institutions. You can ask people now that have been placed there. Oh, it was just going to be for three months. That's what the time frame was. Two years later there is still no place in the community that's been developed. It's an out of sight, out of mind thing and Betty knows that better than anybody and so do the other folks that have lived there.

Jeff: Were you involved with the actual day of the move when Betty came out of the institution?

Jean: No, I was involved in the move when she left her home to go into a residential setting but not when she left the institution. I didn't know her when she was in the institution. I met her shortly after.

Jeff: Did you see others on that day when they were moved into the community for the first time.

Jean: I was at a few residential settings when people came for the first time.

Jeff: What kinds of things do they bring with them?

Jean: A trash bag of clothes and whatever would fit into a trash bag. It wasn't a suitcase. It wasn't how I even went to college. It was a trash bag and that was it and the clothes on their back; nothing to hang on the walls, occasionally maybe a picture of somebody from their family. I'm talking about people that lived in institutional settings for 30 and 40 years and their personal possessions amounted to this. I can't even imagine what people think when they think that's enough for somebody to live on and think that it's okay. But that's people with disabilities and people with mental retardation. Didn't bother them, was a mindset. It's not true because as you see people come out and start to gather possessions and start to realize that they have the right to have these things, oh, it might change us. Then you have to deal with we do have responsibilities that go along with your rights but those adjustments come. Those are things that we all learn growing up that we skip that whole thing for people with disabilities. We just kind of said okay you're going to go from here at the age of six to here and now you're going to live the rest of your life there and then we all of a sudden say okay now you can live in the community and you can have some independence and stuff. That's huge step with all this middle stuff in between being missed and all the socialization and learning of socialization being missed, yeah, people were going to have some concerns with that. One of the things that did happen that was at least better is they did in most cases that I'm aware of, people would get a chance to go visit as opposed to just let's pack up your stuff and go. Although that still happens, I'm sure. You're here today and at the end of the day you come home and your stuff is packed up and you leave and you go live someplace else. That's just wrong to do that to somebody and it happened a lot to people when they moved from one place to another. When they started moving people out of institutions into the community they were a little kinder in how they did that.

Jeff: Kinder because—

Jean: They were kinder because they at least took into consideration that you know what we probably shouldn't just take this person and dump them or place them someplace without at least knowing somebody, without at least seeing the place, without having some comfort level of okay I'm going to have a room. There's going to be other people there. They at least had an opportunity

to see where they were going. Whereas when many people were institutionalized they didn't. They were just taken and left.

Jeff: I want to go back to what you were talking about concerning about your board at Apple Creek. You talked about beating with belts and you said the specifics would come to you. Can you think of any other specifics? The type of punishment that was used that people put up with.

Jean: Well, we talked about the abuse that people put up with, with the sexual abuse that they encountered late at night that often happened. Ruby had talked about the tar. She even said at one point that they put white stuff on her. Now I don't know if that was actually feathering and they shaved her. That was another thing that they said that they did for people. They shaved them, they tarred them and again she didn't use that, she said this black smelly stuff. People didn't receive meals when they were misbehaving. Just the lack of treatment, the lack of education, that didn't happen for people. There was limited education if there was any. It always has amazed me to set foot on any institution on a beautiful sunny day and I've been in institutions in other states also and you never see people outside. I always wonder, you find out there is 1500 people living in an institution and nobody is outside. They're all inside and you know it's not air conditioned or it wasn't at the time so I think that was abusive. That people didn't have access to individuals to be able to talk to. I read somewhere a long time ago that for people that lived in institutional settings if they individual contact with another adult that could actually communicate with them on a daily basis it averaged between three to five minutes a day. Out of a 24-hour day that's an overwhelming bit of information. I go to work and I talk to my friends. You drive down the street and you see people talking on a cell phone these days. But people who lived in institutions didn't have that. We would go in and I thought it was abusive when they'd have a TV going and it was facing where the staff was sitting and everybody in their bed were over here. They didn't see the TV. They heard this thing going on up there, if they even heard that. But the TV wasn't for the people that lived there. Just the way people were treated; the lack of respect; the lack of dignity; what greater way to devalue people than to take your whole self-worth and dignity. We have slides of people one of whom I happen to know, and he lived at Apple Creek at the time and there were slides of them taking showers. They showed them coming out of the shower and this before I had been there and I never saw this. But as they came out they would literally go and they'd shower people down or hose them down however they did it. They'd come out and they'd raise their arm and somebody would come by and spray the deodorant on them. Where's the dignity in that? One of things that did happen at Apple Creek with the superintendent when he first started; I believe it was Delaney before the lawsuit actually occurred. When he started there he decided that no longer were the staff going to be allowed to eat different food and in different places. Because the food that they were giving to the individuals that had disabilities was substandard. Whereas the food that the staff was receiving was the food that you or I might eat. So that was another abuse that was going on and I believe it was Delaney that changed that when he went in. He said, nope, no more, you will eat the same thing and you will eat in the same place. You walk in institutional bathrooms and there were no doors. Toothbrushes above the toilets or above the sink that are just out laying on a counter. You wonder if one toothbrush or six toothbrushes were used for twelve different people. You wondered that kind of stuff, oftentimes no toilet paper in some of the stalls. You just wonder about that stuff. What's going on here? You walked out and you knew this isn't right. That's why we worked to change that but it's slow going and we still have institutions where people still live. And is the care better, yes, is it still not dignified, I believe so.

Man: I want to ask one question. Does Akron have SID or SIB??

Jean: SIB severe injuries behavior, people that would hurt themselves. If you look at the diagnosis we have now people with autism, people who have emotional issues and stuff, people with autism if they have sensory issues may do some of those things but if you provide them appropriate sensory input and I know a lot of people don't believe in that but I've seen it work for folks but if you provide appropriate sensory input the severe injurious behavior stops or it's reduced greatly. If you provide people things to do it doesn't happen. My friend, Ruby, there were a few times that she smacked herself when she would get frustrated and I looked at her at one point and I said, "Why did you do that?" She said because I'm so mad at what just happened and I said, "Why would you hit yourself?" Grab the pillow and hit that and she just said but I'm so mad. Ruby did that a lot more when she was in the institution. I only saw it and I knew Ruby for ten-twelve years, I only saw it two or three times and she spent a lot of time with my family and me. I only saw it maybe once or twice when she was extremely frustrated. I have a sense it went on a whole lot more when she was living in an institutional setting with absolutely nothing to do. I think that's what happens with people when they sit there and they're idle and they start rocking and they start doing things to just know that they exist because nobody else seemed to notice it.

Jeff: Did you have any experience with cigarette smoking concerning institutions?

Jean: Everybody smokes in institutional settings, all the staff did. There were cigarettes everywhere. I mean it smelled like cigarettes every place. Some of the residents did but they were isolated and they were limited on how much they could smoke. Five packs a day but if you are a person that wanted to do that you might get one cigarette in the morning and one in the afternoon. So it was a violation of the individual's rights, that's for sure. It was okay for the staff but it wasn't okay for the residents because it wasn't healthy for them I suppose. But everybody else made that choice for themselves.

Jeff: Did you ever see cigarettes used as reinforcement?

Jean: Yes, cigarettes were—I saw that in some of the programs that I reviewed when we were at Gallipolis that they were actually used as program reinforcers for individuals which is very interesting to me because I'm a nonsmoker and always have been. But yes, they were used as reinforcers for people.

Jeff: What percentage of those you've seen reintegrated into the community smoked?

Jean: That would be a number I'm not sure I could come up with for you. I would say half, probably initially, many of whom quit but I'm not sure why, if they quit because it was a residential home situation that they quit. I think some of them quit because they had other things to do. I just think cigarette smoking passed the time for a lot of people. When people have other things to do they don't smoke. I think a lot of people that smoked in institutional settings it was because they had nothing else to do. And again if the staff were smoking it was the same thing with the keys. We gather the keys because then we look like everybody else. If we start smoking we look like everybody else and nobody knows who we are. There were times I was in institutional settings and you know staff was insulted because you didn't know if they were staff or a resident. I thought that was a cool thing that people kind of fit in. But that time staff would be insulted.

Jeff: You talked about people coming from Gallipolis back to Akron. Gallipolis is in southern Ohio, Akron is in north eastern. Can you describe how the decision was made which institution people would be sent to?

Jean: I think that was a parental choice. I do know the reason that we went to different institutions to identify what people would come back to Summit County would be because either their families originally were from Summit County or the families now lived in Summit County. That's how they would be coming back to the Summit County area. I don't know how people got there. Again the records that I reviewed, they didn't even talk about that stuff. They might have

said that they were dropped off when they were six if I got anything along that line; but never why or how or anything like that. I know in Ruby's case, my friend Ruby, her mom died in childbirth with a younger sibling. There were six kids. Ruby happened to be a slow learner, she was mentally retarded and her dad couldn't take care of her any longer. So the rest of the kids stayed home and Ruby was placed in the institution. I can't even imagine how devastating that was to her as well as her siblings to think am I next. But even in dying right up until the time that Ruby died she loved her dad dearly. She didn't know her mom because she was very young when her mom died but loved her dad dearly and wanted to be buried with her dad which we were able to do for her. Because he would come back and visit but that's what they told them to do; he had no choice and if he was going to take care of the other five kids he was told that he had to do this. She was never bitter to him for that which to me is amazing even as an adult she wasn't bitter.

Jeff: Describe family involvement as you know of it both for those living in institutions and processed with community reintegration. Did the family have to change or anything you'd like to say about that?

Jean: There have been some families that I have met that were very vocal about not wanting their son or daughter to leave the institution. When they did even when they left to a larger setting of 20 people I would talk with them afterwards and they say, "Wow, it is so different. My daughter has so much more access to the community. She doesn't live that far from me." Obviously when people move back to Summit County if their family is here, family has that opportunity to be involved. Do they always? No, for whatever reason sometimes they choose not to. But more often than not if there is still family they do get involved at least to stop and see them. They learn that they're not responsible for the person's financial stuff, they've learned that. They're not even responsible for finding a place for the person to live. The community situation is going to pick up that stuff and I think sometimes once they get that comfort that feeling of comfort they get involved because then they can just be a family person, member with some of the individuals. But it doesn't always happen. There are people that still seek out family and they never see them. And then there are family that want to be involved, that you don't necessarily want to be involved. They're not necessarily the most quality people to be involved in an individual's life.

Man: Can you talk about the experiences you have had seeing clients be able to reconnect with some of that and maybe the forgiveness they're able to ascertain and connected to the community living situation as opposed to institutions.

Jean: In all fairness for people that I've met that have lived in institutional settings I don't think I've ever met anybody, maybe one person that was truly angry at their family for where they were placed. The forgiving part either occurred or they were never angry at them. They were angry at what happened at the institutions but I've never heard people talk poorly about family and maybe it's because, even with Ruby, her dad placed her and she saw him occasionally. He was still her dad. And for a child that's abused they say that they still go back to the abusive parent because they're still their parent. Maybe that has something to do with it but I've never really seen anyone who was totally bitter toward their family member. Except for maybe the guy that was placed by his wife because he had epilepsy and the seizures brought on a lot by his allergies and stuff but he ended up having epilepsy. He was a little bit upset with the fact that he lived the rest of his life, today you couldn't do that. You just can't take guardianship away from somebody like that. Other than him I don't think most people were bitter. The resiliency for people with disabilities is an asset that I think we take for granted. They will go and live in and I'm not saying that everybody is happy and all that stuff that you read about. I'm saying that people are resilient and they adjust to where they're placed. The individuals that I've met can tell you that their life is a whole lot

better when they move in the community and if they get family involvement that's just icing on the cake for them. For those individuals that have had that it's been wonderful to be able to share holidays to call and just say hi to. It's added another dimension to their life that they may never have had if they continued to live in an institution.

Man: Can you speak about parents who have a lot of guilt having done what the doctors told them now trying to change that ??

Jean: Not being a parent of a person with a disability that's kind of a hard thing. There are people that I know that have had a son or daughter that live in an institutional that have moved them into a community setting and were very glad that they did. Do I think there was probably guilt that they lived with? Yes, should they, no absolutely not because as we talked about earlier there were no choices. People were told by doctors this is what you need to do this will be best for your family. Sometimes it was even a harder decision to make to have them come back to the community because they were then going to have to deal with all that guilt. But they did it and I have to credit them for that. You would have to talk to parents themselves to see what the guilt was like because I can't even imagine but I would hope that they would have credit in themselves enough to say that you know what I made a choice given my alternatives, my options but I also made a choice when I saw that it was a better option and so I kept trying to improve the life for my son or daughter. Some of those folks were there every week visiting their son or daughter which is kind of bizarre to me when you have a six year old to think that once a week is a lot but it was when you had to travel across the state to get to see somebody sometimes. They had a lot to live with. So I'm sure that the guilt was just not having your son or daughter grow up in your house was a lot and some of the siblings too. One day they would have their brother or sister home; and the next day they weren't and why was that them and not me. Just because they had some issues in learning that could have easily just been me and that wasn't fair. I'm hoping that people either talk to folks and get over that guilt because they shouldn't have it. They just need to help the person now move on so that life is better for everybody including them.

Jeff: Jean, you talked about Ruby's burial choice ?? Did you have any experience with what happened to people that passed away within the institution?

Jean: Yeah, people that were indigent that passed away within institutions were cremated oftentimes or buried in a plot without any marker. They were just gone. Even today in our community people that are indigent are oftentimes cremated and their ashes are put into what is called the common pot and I have a sense that's what happened at institutions for people that were cremated. Even in death there was no individuality.

Jeff: Did you see the cemetery at Apple Creek?

Jean: I did but I couldn't even tell you where it is. Apple Creek is huge grounds. I do remember seeing that but it's been a while since I've seen that. But I know that there were not markers for people. It was just here today and gone tomorrow. Was there ever grief counseling for any of those folks? Their friend that was sleeping next to them for 40 years is gone. Did anybody ever talk to those folks about and then talk about self-injurious behavior I imagine that they saw a lot of that for people that were grieving because nobody ever talked to them about it because heavens you're a person with a disability. You can't possibly feel for that person that lived next to you. Not true, there are so many people I know that to this day grieve. Ruby was one of them. When her dad died she grieved every day I bet. Even though she didn't see him that much growing up. It was a difficult thing for her because he was important to her. So why wouldn't we do grief counseling for people; but we don't. We're starting to do some of that now because we're starting to acknowledge the humanness of everybody that we work with.

Jeff: You talked about sexual abuse; was sexuality allowed in institutions?

Jean: No, not at all. There were men and there were women and we still have that issue in the community unfortunately. Sexuality was not allowed in institutions. People were not allowed to be together, spend time together without supervision. I know they weren't encouraged if people showed interest in staff opposite sex staff they were discouraged either through program or medication to not be involved with people, not be involved with staff. They needed to have involvement with their typical peers but even —I'm being sarcastic when I say that because I never understood typical peers and I've said that for all the years I've worked here. My peers are people that I have things in common with. They're not people that I have a common IQ with because I don't know the IQ of anybody that I deal with. But in an institution setting even in settings today in the community we still place people in situations where we say that they should be relating to their peers. Well, who's to choose who my peers are? Why should we do that for other people? In the sexual issues people's peers should have been whoever they were attracted to and given the opportunity to learn how to deal with those feelings. But they weren't, they were stifled. They weren't supposed to be sexually involved. I know and I've read that there were operations that were performed on people so that they wouldn't be sexually active or if they were they wouldn't get pregnant. We just did horrific things to people. They were asexual I think in the minds of many people.

Jeff: Are there other areas of Betty's life or your personal experience over the last 26 years that we haven't touched on that you'd like to cover?

Jean: I can't think of anything right now. I'm just looking forward to you guys meeting Betty. Wish you could have met Ruby.